Early Check

Expanded health screening for your baby

The Early Check Team

Early Check was developed by investigators in the Center for Newborn Screening, Ethics, and Disability Studies at RTI International (www.rti.org), a nonprofit research institute with headquarters in Research Triangle Park, NC, USA. We are a multidisciplinary team with expertise in medical genetics, pediatrics, laboratory testing, psychology, genetic counseling, health communication, informed decision-making, ethics, family adaptation, registry development, special education, and child assessment. Our partners include the University of North Carolina at Chapel Hill, Duke University, Wake Forest School of Medicine, and the North Carolina State Laboratory of Public Health (NCSLPH).

www.earlycheck.org

Newborn Screening Background

Newborn screening (NBS) is designed for presymptomatic identification of conditions for which there are effective treatments that must begin early. The Department of Health and Human Services Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) provides guidance to state health departments for conditions to include in NBS—the Recommended Uniform Screening Panel (RUSP)—with four primary considerations: (1) the condition is a significant public health problem; (2) there is a cost-effective and accurate laboratory test; (3) treatments exist with proven efficacy; and (4) states are capable of screening and follow-up.

Currently, 34 conditions are on the RUSP. Many other conditions fall short of the RUSP criteria but are of great interest to families and health care providers, who argue that early identification could result in benefits for both children and families. And as technological advances continue to bring down the cost of screening for rare disorders, advocates are increasingly asking, “Why not screen for them?”

Because most conditions nominated for NBS are rare, researchers have difficulty identifying enough babies to test the benefits of presymptomatic identification and treatment. As a result, the ACHDNC often lacks the information needed to make evidence-based recommendations.

Our plan is to offer Early Check to all birthing parents in North Carolina. If parents accept, this would provide expanded screening for the approximately 120,000 babies born in North Carolina each year.

Don Bailey, PhD, Early Check principal investigator

Early Check Funding

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Questions about Early Check?

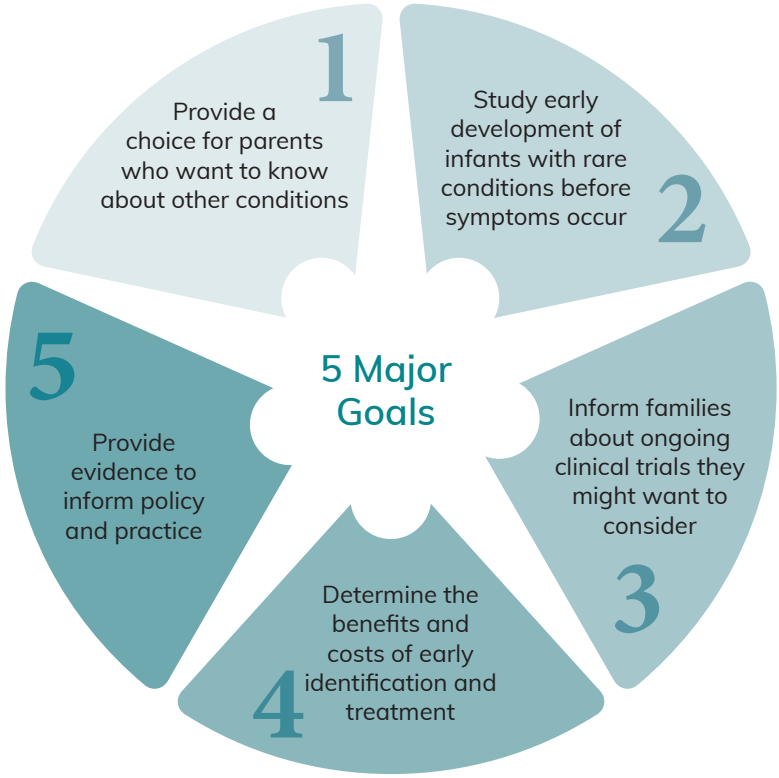
Email: **support@earlycheck.org**

or call: **866-881-2715**

Early Check

The Early Check research study offers a way to study the benefits of NBS for rare disorders so that policy makers and state NBS programs can make good policy and practice decisions. Early Check is a voluntary program that, with parent permission, screens a carefully selected panel of conditions under a research protocol. Initially we will screen for two extra conditions beyond regular newborn screening: spinal muscular atrophy and fragile X syndrome. Both are rare conditions that need more research on effective treatments.

If the Early Check research study is successful, it could have a game-changing impact on state and national policy by accomplishing five major goals:



Year	Primary Activities
2018	Program launches in North Carolina and seeks parental permission for screening; identifies screen-positive children; implements follow-up services, surveillance, and treatment studies.
2019	Continue outreach, screening, and follow-up in North Carolina; modify protocol based on lessons learned; consider addition of new conditions.
2020	Continue screening program; refine or expand as necessary; develop sustainability plans.
Beyond 2020	Sustain collaboration to continue funding innovative approaches that impact the continuum of care for newborns and their families.